

# **Stigma: A Barrier Created by Limited Access to Care and Health Education on Hepatitis C (HCV) Testing and Treatment within the Puerto Rican Population.**

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## **i. Abstract**

Hepatitis C (HCV) is a chronic disease that progresses slowly and has become increasingly prevalent in PWIDs residing in Puerto Rico. Limited access to healthcare and health information has contributed to the stigma surrounding HCV and persons who inject drugs (PWIDs). The systematic review aimed to understand how social determinants of health, limited access to care, HCV education, and stigma affect the overall health of individuals with HCV, especially at-risk populations of people who inject drugs (PWIDs) in Puerto Rico. The review emphasizes the importance of local and federal government agencies taking action to fund and develop HCV health programs for the public and healthcare providers.

**Rationale:** Awareness and knowledge of HCV are crucial to reducing stigma and negative attitudes towards PWIDs in Puerto Rico. Educating people about HCV can reduce stigma and increase testing and treatment rates among PWIDs.

**Objective:** This study investigates existing evidence-based information on the connection of stigma on Hepatitis C (HCV) negatively impacting testing and treatment in Puerto Rico among PWIDs and the need for government funding for prevention and treatment programs to address HCV stigma in Puerto Rico.

**Keywords:** Puerto Ricans; Chronic Hepatitis; Hispanic population; Hepatitis C; Puerto Rico; Stigma; HCV stigma in healthcare; HCV

## **ii. Introduction**

Viral hepatitis is a common virus in the U.S.; it is caused by Hepatitis A, Hepatitis B, and Hepatitis C (CDC, 2021). All three viruses can cause acute liver diseases (Naga Swetha Samji, 2017). Hepatitis C is known as the “silent killer” due to its nature of being asymptomatic for decades. If Hepatitis C (HCV) is left untreated, it can cause damage to the liver, liver failure, and ultimately death (Soto-Salgado, 2012 ). Symptoms of HCV can range from mild to severe, with few to no symptoms, to complications from the virus that may require hospitalization. Medical procedures outside the U.S., body piercing, organ transplants, dental work, sex with an infected person, mother-to-newborn transmission, adults who were born between 1946 and 1964, blood products, tattooing, donated organs, and dialysis are means of contracting HCV. However, intravenous substance abuse is a more common way of acquiring HCV (Carrion, 2011) and is transmitted through direct contact with blood carrying the virus (Watson, 2022). Early detection and treatment of Hepatitis C (HCV) would mean a chance for better health outcomes (The Mayo Clinic, 2023).

## **1. The Effects of Stigma on People with HCV**

The idea that HCV is acquired through shameful relations and deviations such as IV drug use creates a stigma of the disease. The behaviors and beliefs surrounding HCV can lead to isolation from family and friends, discrimination in healthcare and places of employment, strongly impacting the diagnosis and treatment that affect an individual's quality of life (Marinho, 2013). Lekas et al. (2011) study focused on HCV stigma in healthcare and practitioners' negative views of individuals with HCV, and the participant's perception of HCV as a contagious virus transmitted by casual contact that led to the participants to self-isolate and self-stigmatize, the findings proved that there is an HCV-related stigma (Lekas H. , 2011).

## **2. HCV Stigma in Healthcare**

Stigma in healthcare is a social phenomenon that influences the direction of illness and leads to inappropriate treatment, avoidance of an individual with HCV, discrimination, and exclusion in marginalized groups (Saine, 2021). People who have a history of injection drug use (IDU), leads to them being stigmatized by healthcare practitioners, which creates an obstacle to receiving proper care (Díaz D. , 2020). Hernández D et al. (2017) study found higher rates of HIV and HCV in Puerto Rican PWIDs due to individual and socio-structural factors, including stigma, and that medical professionals hold stigmatizing beliefs about certain chronic conditions, such as HCV. Developing a relationship with individuals living with HCV and including them in their healthcare may be an important step in addressing stigma as an obstacle to treatment (Treloar, 2013)

### **3. HCV in Puerto Rico**

HCV rates are higher among Puerto Rican PWIDs born on the island (86%) compared to those born in the US (70%), according to researchers at Mount Sinai Hospital in NYC. Lack of access to drug treatment programs and HCV services may contribute to the high incidence and prevalence of HCV in the Puerto Rican PWID population (K Arasteh, 2020). In 2023, the prevalence of HCV was particularly high, estimated at 76.5-78.4%, with the highest percentage of people affected being PWIDs, due to limited HCV diagnoses, lower treatment rates, referrals to treatment, negative experiences with health care providers, and barriers to healthcare (Mate-Gelabert, 2023). Silvia-Diaz et al. (2020) explored the health needs of the people in Puerto Rico's health and concluded that Puerto Ricans, have poorer health outcomes than other Hispanics and non-Hispanics in the U.S. (Díaz, 2020).

Perez et al. (2007) revealed high rates of HCV infection among at-risk individuals of Puerto Rican origin living in San Juan, Puerto Rico. They suggested that HCV is a serious public health issue that requires further investigation into the lifestyle and behaviors of individuals who have contracted it. Given the surge in HCV infection rates in Puerto Rico, an effective HCV prevention and treatment plan must be implemented to eliminate the virus from the region (Perez, 2007).

### **4. Medicaid Restrictions in HCV Care**

Although HCV has been recognized as a global health concern, Puerto Rico continues implementing criminalization approaches toward HCV care (Varas-Díaz, 2010). Between 1998 and 2002, the Puerto Rican government reduced treatment options for PWIDs by 41% and disguised it as "health reform" (Varas-Díaz, 2010). In 2014, Medicaid programs restricted HCV treatment where patients were required to provide sobriety documentation, proof of severe liver disease, and consult a gastroenterologist. The restrictions included pre-authorization for HCV treatment and limited prescription privileges to specialists or HCV-certified primary care physicians, which resulted in delayed HCV diagnosis and treatment, especially for at-risk populations (Mate-Gelabert, 2023). Since HCV medications are incredibly expensive, Medicaid had to limit access to them, making them available only to the sickest patients (Rodriguez, 2018). The discriminatory restrictions left many Puerto Rican PWIDs untested and untreated (Varas-Díaz, 2010)

### **5. The Importance of Formal HCV Health Education**

Most people are unaware of how HCV is transmitted, which leads to fear and stigmatization of those infected with the virus. Participants in the

study frequently used terms like "uneducated" and "ignorant" to describe the public's limited awareness of HCV (Lekas H. , 2011). Data collected from the study by Soto-Salgado et al. 2012 included Puerto Ricans who resided in New York City and Puerto Rico between the ages of 21 and 64, concluded that a substantial number of adults in the study indicated insufficient knowledge of HCV, especially on the transmission route (Soto-Salgado, 2012 ).

Anti-stigma education would bring information that cancels out the false beliefs about HCV by replacing them with evidence-based information on HCV (National Academies of Sciences, 2016). Public health intervention efforts must address the perception of HCV, society's stigma, and self-stigmatization. During the Interferon HCV treatment era, HCV education significantly impacted at-risk populations by improving HCV awareness, care coordination, HCV treatment, and better therapy response (Partida, 2022).

## **6. Problem Statement and Research Question**

The review examines the limited HCV education and access to care that create stigma among PWIDs and affect their decision to seek HCV testing and treatment, leading to adverse health outcomes.

## **7. Research Question**

Does limited access to HCV care and health education create stigma barriers to HCV testing and treatment among PWID in Puerto Rico?

### **iii. Methods**

## **8. Eligibility Criteria**

The systematic review included articles that researched the correlation between HCV and stigma in Puerto Rico. The participants in the articles used were required to be of both genders, between the ages of 18 and 64, and not incarcerated. Furthermore, each article had to be written in English and pertain to HCV, stigma, Puerto Rico, and PWIDs to be deemed eligible for inclusion in the review. Given the abundance of information on this subject, only some selective sources were considered - only those that

met the eligibility criteria were included. These standards included date of research, language, location (within the U.S. and specifically Puerto Rico), and age range of participants (18-64); incarcerated individuals were excluded.

## 9. Information Sources

In the review, an online search strategy using Google Scholar to gather information from publicly available sources containing pertinent data and information related to HCV, Puerto Rico, and stigma. All journals and articles used were peer-reviewed, and all information was based on existing scientific research studies. The review process allowed for a thorough analysis of each publication's credibility and reliability. The search used relevant terms such as Puerto Ricans, chronic hepatitis, the Hispanic population, Hepatitis C, Puerto Rico, stigma or HCV stigma in healthcare, and HCV education to gather articles and journals from various sources. Table 1 below outlines the sources from which we retrieved our information.

**Table 1 -Information Source Chart**

Publication	Author(s)	Data of Search and Database
Hepatitis C virus care cascade among people who inject drugs in Puerto Rico: Minimal HCV treatment and substantial barriers	Pedro Mateu-Gelabert et al. (2023)	Date of search- September 12, 2023 Database -Google Scholar Website - <a href="https://doi.org/10.1016/j.dadr.2023.100178">https://doi.org/10.1016/j.dadr.2023.100178</a>

to HCV care		
Stigma in health facilities: why it matters and how we can change it	Nyblade, L et.al. (2019)	Date searched: May 14, 2022 Database: Google Scholar Website: <a href="https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-019-1256-2#article-info">https://bmcmmedicine.biomedcentral.com/articles/10.1186/s12916-019-1256-2#article-info</a>
Understanding Barriers to Hepatitis C Virus Care and Stigmatization from a Social Perspective	Treloar, C et al. (2013)	Date of search: May 14, 2022 Database: Google Scholar Website: <a href="https://doi.org/10.1093/cid/cit263">https://doi.org/10.1093/cid/cit263</a>
When "the Cure" Is the Risk: Understanding How Substance Use Affects HIV and HCV in a Layered Risk Environment in San Juan, Puerto Rico	Hernández, D et al. (2017)	Date of search: May 14, 2022 Database: Google Scholar Website: <a href="https://pubmed.ncbi.nlm.nih.gov/28891344/">https://pubmed.ncbi.nlm.nih.gov/28891344/</a>
Hepatitis C, stigma, and cure	Marinho, R et. al. (2013)	Date of Search: May 20, 2022 Database: Google Scholar Website: <a href="https://pubmed.ncbi.nlm.nih.gov/24187444/">https://pubmed.ncbi.nlm.nih.gov/24187444/</a>
Stigmatization of Illicit Drug Use among Puerto Rican Health Professionals in Training	Varas-Diaz et. al (2010)	Date of search: May 20, 2022 Database: Google search Website: <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2877284/">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC2877284/</a>

## 10. Search Strategy

A search on Google Scholar was conducted to find published literature on the topics of stigma or HCV stigma, Hepatitis C or HCV, Puerto Rico, Puerto Rican, access to care, limited access to care, HCV health education, HCV stigma in healthcare, and Hispanic population. This search yielded 285 results. To be considered for inclusion, the articles had to involve participants or groups who were PWIDs, had HCV, and had experienced stigma because of their chronic conditions. Only articles that provided prevalence and incidence rates were included in the review.

## 11. Selection Process

A sole reviewer selected articles aligned with the search criteria. Each study was evaluated for quality and credibility. The chosen studies delved into HCV stigma, HCV, stigma, access to care, HCV health education, and Puerto Ricans, with an emphasis on the pertinent region of Puerto Rico (both urban and rural). It is important to note that the search was limited to articles and journals in English, participants aged 18-64, studies conducted within the U.S. and Puerto Rico only, and excluded incarcerated participants, irrelevant articles, and non-full text studies. The research identified seven relevant articles after careful review and filtering using specific criteria.

## 12. Data collection process

During the data collection process, a single reviewer examined each article. The articles selected contained information about the authors, year of publication, year due for review, and the type of guidelines. The collected data included past and current rates of the Puerto Rican population and prevalence rates of HCV in Puerto Rico, as well as percentages of HCV awareness among certain groups (PWIDs) in Puerto Rico. Other details such as repetitions, frequency, duration, and qualifications were also gathered. The data collected through these methods were carefully analyzed to support research hypotheses and draw conclusive insights on the study's objectives

## Data Items

**Table 2** -Lists the author, common themes, and the summary of each study.

Author and Date	Themes	Summary of studies
<a href="#">P Mateu-Gelabert</a> , et al. (2023)	<ol style="list-style-type: none"><li>1. Lack of HCV information.</li><li>2. Lack of access to HCV care</li><li>3. Negative</li></ol>	<p>Participants in Puerto Rico were asked questions on factors that would prevent them from getting treated for HCV.</p> <p>Participants</p> <ol style="list-style-type: none"><li>1. Felt unwelcome at medical facilities due to</li></ol>

	<p>interactions and stigma felt by medical providers.</p> <p>4. Stigma felt by individuals with HCV.</p>	<p>their HCV status and felt stigmatized.</p> <p>2. Felt stigma affects their decision to get treated.</p> <p>3. Had lack of awareness and accessibility to HCV information and services and treatment restrictions</p>
Hernández D, et al. (2017)	<p>1. Lack of HCV education and treatment services</p> <p>2. Lack of HCV medical care access</p> <p>3. Puerto Rican IDU's feeling of stigma felt by healthcare professionals.</p>	<p>The research concluded that IDUs in Puerto Rico experience.</p> <p>1. Various issues that affect linkage to HCV care treatment</p> <p>2. Stigma that impedes treatment and testing</p> <p>3. Stigma felt by medical professionals creates a reluctance to disclose the status.</p> <p>4. Lack of HCV education and medical and treatment services increases HCV rates and creates stigma.</p>
Treloar, C et al. (2013)	<p>1. Stigma felt by healthcare professionals.</p> <p>2. Stigma impacts the decision to get treatment.</p> <p>3. Individual feelings on stigma</p> <p>4. Stigma creates a barrier between individuals and medical providers.</p>	<p>The study brings to awareness on how</p> <p>1. Stigma impacts decision-making for treatment and when to engage.</p> <p>2. The disconnect between the personal experience of HCV and the assumptions of medical providers affects treatment.</p> <p>3. Healthcare settings are where individuals most report to have experienced stigma.</p> <p>4. Education on HCV awareness is needed.</p>
Varas-Díaz, N. et al. (2010)	<p>1. Stigmas affect the quality of life.</p> <p>2. Health professionals' negative attitudes and stigma affect HCV treatment.</p> <p>3. Denial of the basic standards of care to specific</p>	<p>The qualitative results revealed</p> <p>1. Puerto Rican healthcare professionals in training had stigmatizing attitudes toward illicit drug users.</p> <p>2. HCV education is needed to provide awareness.</p> <p>3. Stigma impacts the treatment of those with HCV.</p>



	<p>populations (IDUs )</p> <ol style="list-style-type: none"> <li>4. Stigma influences the decision to get treated.</li> </ol>	
<p>Nyblade, L. et al. (2019)</p>	<p>The research examined how stigma in healthcare facilities can contribute to</p> <ol style="list-style-type: none"> <li>1. Not seek treatment due to stigma.</li> <li>2. The lack of knowledge regarding certain conditions</li> <li>3. Disclosing stigmatizing status</li> </ol>	<p>The findings showed</p> <ol style="list-style-type: none"> <li>1. Stigma in health facilities is evident.</li> <li>2. Stigma negatively impacts patients' health and eagerness to seek treatment.</li> <li>3. Disclose their health status due to fear of being stigmatized by health professionals.</li> <li>4. Medical professionals have stigmatizing views towards certain conditions.</li> <li>5. Stigma interventions are needed to reduce stigma.</li> </ol>
<p>Marinho RT, et al. (2013)</p>	<ol style="list-style-type: none"> <li>1. HCV impacts socialization and quality of life.</li> <li>2. HCV Stigma is associated with anxiety and fear of transmission.</li> <li>3. Stigma causes social isolation.</li> <li>4. Stigma affects diagnosis and treatment.</li> <li>5. Lack of adequate HCV information creates stigma among health professionals</li> </ol>	<p>Marinho researched on how</p> <ol style="list-style-type: none"> <li>1. Stigma impacts how the virus is viewed.</li> <li>2. Stigma influences the decision not to seek testing and treatment.</li> <li>3. Stigma affects a person throughout HCV.</li> <li>4. Healthcare professionals' perception of HCV might influence the treatment of HCV patients.</li> </ol>
<p>Lekas, H. M., et al. (2011)</p>	<ol style="list-style-type: none"> <li>1) HCV as an added layer to HIV was more stigmatizing than HIV alone or both.</li> <li>2) How felt stigma from health care providers is due to a lack of understanding of behaviors among IDUs and HCV as a disease</li> <li>3) Experiences of felt and enacted stigma among former and</li> </ol>	<p>The study examined</p> <ol style="list-style-type: none"> <li>1. Which of the two conditions (HIV/HCV) were stigmatized the most</li> <li>2. Participants' perceptions of their statuses.</li> <li>3. Stigma felt by participants among their peers, family, and medical professionals.</li> <li>4. Lack of knowledge of HCV creates negative perceptions and stigma.</li> </ol>

### **13. Study Risk of Bias Assessment**

The seven selected studies underwent thorough data extraction by multiple reviewers and employed diverse techniques to gather information from participants and related research. Table 2 details the specific approaches utilized. Each study focused on impartiality, and the authors comprehensively analyzed the evidence on HCV and stigma. Various survey methods were employed to mitigate potential biases, and participants did not experience any risk or harm. The findings of each study and the present review agree with those of previous systematic reviews, with no contradictory or novel evidence uncovered.

### **14. Effective Measures**

The research were selected and evaluated using the PRISMA method. All articles were carefully assessed for their reliability and validity. Each article had to have a study design and methodology that included sample/variables, demographics, inclusion, and exclusion criteria to clearly explain the findings. The authors used various methods to determine the perspective's effectiveness, such as objective analysis, qualitative and quantitative assessments. The population of each study was determined by analyzing inputs and outputs, and research measures were reviewed for accuracy.

### **15. Synthesis Methods**

The synthesis process began with inputting all the article's year of publication, authors' names, data collection methods, and titles into an Excel spreadsheet. Duplicates, incomplete text, and irrelevant articles were removed to ensure accuracy. The remaining articles were then screened for relevance. The selected articles included various research methodologies such as observational and interventional research, respondent-driven sampling methods, systematic reviews, non-randomized controlled trials, before-and-after studies, case series, and individual case reports. Additionally, ethnography, qualitative and quantitative content analysis, and qualitative studies with additional methodologies were included. Only articles with titles and abstracts in English were included in the final list to ensure consistency.

### **16. Reporting Bias Assessment**

A thorough evaluation of each study was carried out to gather relevant and meaningful information. The approach involved an extensive

online search on Google Scholar. The search used specific keywords: Puerto Ricans, Chronic Hepatitis, Hispanic population, Hepatitis C, Puerto Rico, Stigma, HCV stigma in healthcare, and HCV education to ensure that only studies pertinent to the review were included in the analysis. This process was executed with a focus on the details of each article, such as year of publication, characteristics of participants, and region of study, leaving no room for potential biases. As a result, the findings are impartial and can be relied upon with confidence that there was no risk of bias.

## 17. Certainty of Assessment

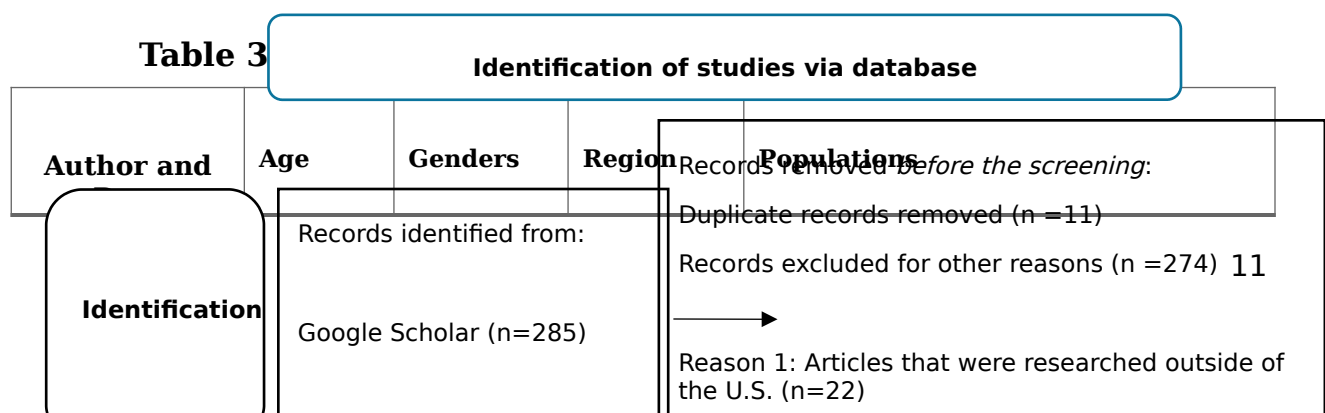
The PRISMA technique was utilized to conduct this research, which entails screening and selecting studies based on pre-determined criteria. This process involved excluding studies in other languages, duplicates, and incomplete texts. The evidence used in this review was examined to ensure that it is evidence-based and free from misleading information by cross-checking relevant evidence-based literature on HCV and stigma.

## iv. Results

### 18. Study Selection

The Google Scholar search identified 285 articles. The search was executed using specific keywords: Puerto Ricans, Chronic Hepatitis, the Hispanic population, Hepatitis C, Puerto Rico, Stigma, HCV stigma in healthcare, and HCV education. The articles' titles, abstracts, and introductions were reviewed to ensure their relevance to the research topic. Overall, this screening process ensured that relevant and reliable sources were selected for the research, and the study outcomes were expected to be accurate and insightful. Figure 2 shows the identification of the studies used for the review.

**Figure 2- Study Selection Flow Chart**



<p><b>P Mateu Gelabert, et al. (2023)</b></p>	18 years and >	Both genders	Puerto Rico	150 Puerto Ricans participants who were PWIDs and have or at risk for HIV/HCV who have experienced challenges in linkages to care to and retention in care.
	24-55 years of age	Both genders	San Juan, Puerto Rico	501 Participants were healthcare professionals from multidisciplinary teams in Puerto Rico.
Varas-Díaz, N. et. al (2010)	21 years and older	Both genders	Various hospitals and universities throughout Puerto Rico	The general population with HCV has experienced stigma from medical providers
Trelaor, C (2013)	21 years and older	Both gender	Global	132 participant's HIV/HCV-coinfected men (69%) and women (31%) U.S. born Puerto Ricans and Puerto Ricans born on the island. Who have experienced multiple layers of stigmatization due to coinfection.
Lekas, M (2011)	20-69	Both genders	New York City and Puerto Rico	Healthcare providers and patients who have various chronic conditions
Nyblade, L. et. al. (2019)	21 and older	Both genders.	Global-United States, Canada, and Ghana	General population with HCV positive status
Marinho RT, et. al. (2013)	No age range was mentioned.	Both genders	Globally	

## 19. Results of Individual Studies

Table 4 depicts the results for each study. The extracted data from each article included the author, title, study aims, data collection methods, study type, and conclusion.

**Table 4.** Results of Individual Studies

Title	Author	Research Methods	Study type	Study Aims	Conclusion
Hepatitis C virus care cascade among people who inject drugs in Puerto Rico: Minimal HCV treatment and substantial barriers to HCV care	Mateu-Gelabert, P	Respondent-driven sampling method Referral Sampling	Quantitative/ Qualitative	The goal of the study was to describe the HCV cascade of care among IDUs in Puerto Rico, And to identify gaps and barriers to HCV care. With stigma and perceptions presenting as a barrier to HCV care.	The study identified HCV barriers that included lack of HCV testing, linkage to care, knowledge of treatment and testing, and treatment restrictions. Other barriers included transportation, drug abstinence, and stigma.
Stigma in health facilities: why it matters and how we can change it	Nyblade, L	The study used the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines.	Systematic review	The research assessed the impact of stigma in healthcare and how interventions to reduce stigma in health facilities and address multiple stigmatized health conditions.	The study concluded that stigma in health facilities affects treatment decisions and health outcomes.
Understanding Barriers to Hepatitis C Virus Care and Stigmatization from a Social Perspective	Treloar, C	An online search strategy was conducted using databases such as: Google Scholar WorldCat PubMed CrossRef	Literature review	The review wanted to raise awareness and understanding of stigma and its role in individuals' decisions on "if and how" to engage in HCV care.	The study concluded that stigma directly influences mental and physical health outcomes and the decision to seek testing and treatment.
Understanding How Substance Use Affects HIV and HCV in a Layered Risk Environment in San Juan, Puerto Rico	Hernández, D	Rapid Ethnographic Assessment	Quantitative/ Qualitative	The article examined the individual and social factors that affect HIV/HCV risk among people who use drugs living with or at risk in San Juan, PR.	The research findings suggest that IUDs in PR face various challenges that affect HIV/HCV and impede treatment, linkage to, and retention in care. The challenges were access to prevention, care, and treatment, social isolation, and stigma.

Hepatitis C, stigma, and cure	Marinho, R	Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines	The systematic review	Marinho's article examined the impact of HCV stigma and how HCV is a mental, psychological, familiar, and social disease, with the primary cause being the lack of adequate HCV information, even in the health professionals setting, causing stigma felt by those affected with HCV.	The study concluded that chronic hepatitis C is a disease with the stigma associated with it. People infected with HCV experience stigma, anxiety, and fear of transmission, which causes social isolation and reduced intimacy in relationships, which affects the decision to seek treatment and disclose HCV status. The study also concluded that there is a need to bring awareness of the chance of a real cure and eradicate the virus.
Stigmatization of Illicit Drug Use among Puerto Rican Health Professionals in Training	Varas-Diaz N,	Quantitative/Qualitative methods High-depth interview with Sequential Mixed Method	Qualitative Analysis	The study aimed to explain how social stigma felt by individuals from medical providers is a barrier to treatment in Puerto Rico and how HCV is a stigmatized health condition that continues to be criminalized in Puerto Rico.	The conclusion of the research findings showed that social stigma affects IDUs in Puerto Rico and how stigma further criminalizes them and contributes to the lack of effective treatment from healthcare professionals. It showed that intervention strategies are needed to reduce stigma among health professionals in training to increase better health outcomes on the island.
Felt and Enacted Stigma Among HIV/HCV-Coinfected Adults: The Impact of Stigma Layering	Lekas, H	Qualitative interview	Qualitative Analysis	The article explored the impact stigma layering of HIV and HCV and the experiences stigma felt among former and current injecting drugs with both diseases.	The analysis concluded how coinfecting individuals perceived and felt about having two stigmatizing diseases and how it impacts intervention.

## 20. Results of Syntheses

These studies utilized various methodologies to examine and analyze data, providing valuable insights on HCV and evaluating participants' HCV status. The articles focused on several aspects related to HCV, including the stigma experienced from medical professionals towards people with HCV, the impact of this stigma on HCV treatment, fear of stigma, and how the lack of education on HCV contributes to the barrier of stigma. Each study emphasized the adverse effects of stigmatization from healthcare providers

towards people with HCV, which creates a fear of being forthcoming with their health status (Lekas, 2013, Marinho 2013, Treloar, 2013, Mate-Gelabert, 2023). Overall, these studies shed light on the challenges faced by PWIDs in Puerto Rico and the need for healthcare providers to be more sensitive and informed about stigmatization. The seven articles suggested raising awareness and knowledge of Hepatitis C (HCV) can increase testing and treatment rates, according to the five studies conducted on Puerto Ricans who inject drugs (PWIDs) and stigma.

To conduct the studies, the researchers used an online search strategy on Google Scholar, PubMed, and PMC, using keywords such as Hepatitis C, Chronic, Therapy, Hepatocellular carcinoma, Hepatic cirrhosis, Interferon-alpha, Ribavirin, Social stigma, and Depression. The review analyzed sixty-five articles on various aspects of HCV, including HCV Natural History, Chronic HCV, HCV quality of life, HCV stigma, HCV therapy, Stigmatization in research, and HCV-related discrimination. Overall, the studies provided valuable insights into the impact of HCV on the quality of life of patients and the role of stigma in delaying diagnosis and treatment. The findings can be used to develop strategies to reduce stigma and improve the quality of life of patients infected with HCV.

Each of the seven studies showed that the lack of information about chronic conditions including Hepatitis C Virus (HCV) leads to stigmas and negative perceptions among healthcare providers, patients, and the public. Health education and HCV services are crucial in reducing HCV rates and addressing the associated stigma. However, there is a severe lack of resources for HCV services in Puerto Rico, leading to a significant challenge. The stigma associated with HCV causes fear and anxiety among individuals with the virus, leading to reluctance to seek treatment. The lack of awareness about HCV is a significant barrier contributing to the stigma. Overall, health education and HCV services are essential in reducing infection rates and addressing the stigma associated with HCV.

In the study conducted by Gelabert et. al. (2023), the goal was to identify gaps in care and barriers in HCV treatment; this included lack of testing, linkage to care, knowledge of treatment options, perceptions of participants, and testing site. Data collected revealed that programs for HCV testing and treatment are necessary to eradicate HCV in Puerto Rico. Descriptive analysis, respondent-driven sampling, multiple-choice questions, and sequential methods were used to collect responses from subjects. For the study, 150 individuals participated, with 84% of participants screened for HCV previously, while others were 87% HCV Ab positive, 72% were RNA positive, 48% were linked to care, 32% were already in treatment, and 58% completed treatment and 71% were cured (Mate-Gelabert, 2023). Factors were included such as barriers to HCV care, as well as concerns about no transportation to treatment, stigma in healthcare facilities, and limited knowledge about HCV treatment sites. The

objective of Gelabert's study was to bring awareness of the need to address the HCV cascade of care, limited diagnosis, treatment uptake, and barriers to HCV care in Puerto Rico.

Hernandez et al. (2017), examined the individual and social factors that affect the lives of individuals who are PWID and living with or at risk for HIV/HCV in San Juan, Puerto Rico. The researchers collected data using the ethnographic approach with 150 encounters, 49 unstructured interviews with the target population (PWID), and 19 interviews with community-based organizations. For the study, field notes, photographs, and interview transcripts were used to analyze recurrent themes. The findings of the interviews concluded that the participants experienced social stigma, limited medical and substance abuse treatment, an increased risk of acquiring HIV/HCV, and a lack of links to care and retention. It also found that new approaches to interventions are needed to improve HCV care engagement rates (Hernández, 2017).

A systematic review by Treloar C et al. (2013) highlights the association between HCV and stigma in healthcare settings and how a positive relationship between HCV-positive individuals and their medical providers will have a positive effect on health outcomes. The study used reviewed forty-six peer-reviewed and evidence-based studies to conclude that the assumptions and stigma health care providers feel towards individuals with HCV influence patient engagement and treatment uptake. For the study, an online strategy was used to generate research articles about HCV and stigma and the barrier stigma creates to seeking HCV care using keywords such as Hepatitis C, injection drug use, stigma, trust, clinical encounter, and patient-doctor relationship.

The study by Nyblade et al. (2019), examined how stigma hinders the quality of healthcare, diagnosis, treatment, and overall health outcomes. The articles used for the research were categorized by disease-specific stigma, and the approaches used as an intervention. The quality of data for each article used was assessed using a 27-item Downs and Black checklist. Each article that scored 14 or above was considered a high-quality study, and the 18-item framework was used to assess the quality of the data in each article. Studies that scored 10 or more were considered high-quality studies (Nyblade, 2019). The Preferred Reporting Items for Systematic Review and Meta-Analyses (PRISMA) were used. The results of the PRISMA search were (n=728) peer-reviewed abstracts that were assessed, with (n=68) articles that went through a full-text review, and (n= 37) met the inclusion criteria. Nyblade's study highlighted stigma and its negative impact on health care, as well as the approaches and methods used to reduce stigma in health settings.



A study by Varas-Díaz et al. (2010) focused on stigma towards PWIDs in Puerto Rico and how stigma is a barrier to care (Varas-Díaz, 2010). For the study, there were (n= 501) participants. In the qualitative stage (n= 80), participants were interviewed using a qualitative survey. Each participant was from various specialties of medicine including nursing, psychology, and social work. The subjects were divided among practicing physicians (n=40) and health students in training (n=40). Quantitative questionnaires were given to (n= 421) health professionals in training (Varas-Díaz, 2010). The results of the study provided evidence of how each participant had stigmatizing beliefs towards PWIDs and how stigma among healthcare and social workers negatively affected those infected with HCV. The study concluded that there's a need for health education for health professionals, and intervention strategies to reduce such stigma towards HCV and PWIDs among health professionals are necessary in Puerto Rico.

According to the systematic review by Marinho, R et al. (2013), the HCV epidemic is a crisis that continues to affect millions of people worldwide. Approximately 170-200 million people have HCV positive, with many not knowing of their HCV status. Another factor of stigma is the lack of health education within the public and amongst health care professionals. The study also provided evidence-based information on how HCV negatively impacts the quality of life of individuals who are HCV-positive, even though there is a cure. The factor Marinho et al. (2013) focused on was stigmatization felt by providers being the main barrier that stands in the way of treatment and prevention. For the study, no participants were used; the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) strategy were done to sort relevant evidence-based articles and journals and keywords such as Hepatitis C, PWID, Cascade of care, Barriers to HCV care, Puerto Rico were used to conduct the search to generate relevant evidence-based studies.

## **21. Reporting Biases**

Out of seven articles used in the study, three had low-medium risk for bias due to limitations faced during the study. P. Mateu-Gelabert et al. (2023) study had limitations regarding the accuracy of self-reported HCV status, history, testing, and treatment. Similarly, Varas-Díaz, N. et al.'s (2010) convenience sampling aimed to examine and diminish stigma related to illicit drug use, and Lekas, H. M. et al.'s (2011) sampling only included certain racial/ethnic backgrounds and underserved minority groups, posing a medium risk for bias. Figure 3 shows the bias risk for each study.

## **Risks of Bias in the Studies**

**Figure 3-shows the levels of risk of bias of the studies.**

<b>Study</b>	<b>Bias due to randomization</b>	<b>Bias due to deviations from intended interventions</b>	<b>Bias due to missing data</b>
<p>Understanding Barriers to Hepatitis C Virus Care and Stigmatization from a Social Perspective.</p> <p>Treloar, C et al. 2013</p>	Low bias risk	Low bias risk	Low bias risk
<p>Hepatitis C virus care cascade among people who inject drugs in Puerto Rico: Minimal HCV treatment and substantial barriers to HCV care.</p> <p>P Mateu-Gelabert, et al. 2023</p>	Low bias risk	<p><b>Medium bias risk</b></p> <p>This study had several limitations. The first limitation was on self-reporting data on HCV testing and HCV history, treatment, and linkage to care. The second was the timeframe of analysis on the HCV cascade of care because it was for a participant's lifetime, so the self-reported data is limited by the participant's recollection of receiving HCV-related services, which they may have received a long time before.</p>	<p><b>Low bias risk</b></p> <p>The data lacked medical record information that could provide a more detailed medical history.</p>
<p>Stigma in health facilities: why it matters and how we can change it</p> <p>Nyblade, L. et al. 2019</p>	Low bias risk	Low bias risk	Low bias risk
<p>Understanding How Substance Use Affects HIV and HCV in a Layered Risk</p>	Low Bias risk	Low Bias risk	Low Bias risk

<b>Study</b>	<b>Bias due to randomization</b>	<b>Bias due to deviations from intended interventions</b>	<b>Bias due to missing data</b>
Environment in San Juan, Puerto Rico  Hernández D, et al. 2017			
Hepatitis C, stigma, and cure  Marinho RT, et al. 2013	Low Bias risk	Low Bias risk	Low Bias risk
Stigmatization of Illicit Drug Use among Puerto Rican Health Professionals in Training  Varas-Díaz, N. et. al. 2010	Low Bias risk	<b>Medium Bias risk</b>  The study's limitations were the lack of convenience sampling, whose purpose was to understand stigma and how to reduce the stigma related to illicit drug use.	Medium Bias risk
Felt and Enacted Stigma Among HIV/HCV-Coinfected Adults: The Impact of Stigma Layering  Lekas, H. M., et al. 2011	Low Bias risk	<b>Medium Bias risk</b>  The limitations of the study were associated with the study's sampling. All the participants were former or current IDUs that belonged to certain racial/ethnic, underserved minority groups.	<b>Medium Bias risk</b>  The study lacked subsets of coinfecting White participants, which was needed for comparison.

## 22. Certainty of Evidence

The present study has utilized seven articles that conducted various data collection methods. The different approaches for four of the studies that used a scientific approach for collecting data were Quantitative and Qualitative surveys, a Respondent-Driven Sampling method, Referral

Sampling design, and Rapid Ethnographic Assessments. Three of the seven remaining articles used the PRISMA method and an online search strategy to find evidence-based and peer-reviewed information for their research. Each article was examined for risk of bias and limitations as depicted in figure 3. Which showed that three out of the seven posed a medium to low risk of bias due to missing information and lack of access to information on the participants, Overall, the seven articles used multiple approaches and methods to ensure reliability and validity such as unstructured interviews, qualitative and quantitative surveys, and sampling methods to prevent bias in the research.

## **v. Discussion**

The current review identified stigma created by limited access to care and health education is a barrier to HCV testing and treatment among PWIDs within Puerto. Findings from the evidence-based articles revealed that the lack of access to care and resources for Hepatitis C in Puerto Rico is problematic in controlling HCV on the island and that individuals with chronic conditions, including HCV and drug use, frequently encounter stigma and discrimination from healthcare providers who may hold them responsible for their actions (Nyblade, 2019). The present review aligned with those of previous systematic reviews that found that stigma does impact HCV testing and treatment and that an increase in health education is necessary to reduce stigma in the public and within the medical field. Since there is limited information on the epidemiology of HCV in Puerto Rico, HCV continues to be problematic on the island, therefore, it is necessary for public health interventions to address the perception of HCV, society's stigma, and access to care for at-risk populations such as PWIDs. HCV is a significant public health concern requiring further investigation into the lifestyles and behaviors of those afflicted with the virus. However, there is limited research on the needs, behaviors, and lifestyles of individuals in Puerto Rico, particularly at-risk groups including PWIDs (Perez, 2007). Improving the awareness of healthcare providers and the public regarding Hepatitis C Virus (HCV) is needed to enhance access to health services in marginalized populations (Samali-Lubega, 2013). It is crucial for more research to be conducted within the Puerto Rican population and for the government to take action in allocating funds and resources to devise HCV prevention and intervention programs that target

at-risk populations such as PWIDs and medical professionals to control and or eliminate HCV in Puerto Rico.

The articles used emphasized the necessity of diminishing stigma towards individuals with HCV or who are at-risk to motivate them to seek necessary medical care (Lekas, 2013, Marinho 2013, Treloar, 2013, Mate-Gelabert, 2023). Each article highlighted the urgent need for improved access to care and resources, and the importance of reducing stigmatization in the healthcare system and the public. Therefore, it is essential to address these challenges to increase the number of individuals seeking testing and treatment for Hepatitis C in Puerto Rico. The findings of this review have significant implications for policymakers, healthcare providers, and stakeholders involved in providing and funding healthcare services in Puerto Rico that address the high prevalence rates of HCV, and to develop prevention and intervention strategies to control and eradicate the virus. Strategies may include supporting research that measures HCV incidence and prevalence in the PWID population, developing needle exchange programs, expanding linkage to care, increasing prescription rights to primary physicians, and expanding access to care and direct-acting therapy. Stigma reduction strategies may include approaches that provide education on HCV for healthcare professionals and skill-building exercises (for healthcare providers). This will help providers to develop skills to work with the target population (PWIDs) and have contact with the stigmatized groups to humanize the individual that is being stigmatized; the approach will help to reduce stereotypes and stigma. While the suggested strategies would improve in reducing stigma and increasing testing and treatment rates, action from the federal government is needed to fund HCV programs and access to care and uplifting of restrictions for physicians and patients in Puerto Rico.

## **Limitations**

One of the main challenges encountered while searching for studies was the considerable lag in publishing articles and journals from the initial stages to the completion of the research. This delay often resulted in the need to revise the articles due to the possibility of information changes that occurred during the waiting period. These limitations were particularly significant when dealing with fast-paced fields, where new developments and insights can emerge rapidly. As a result, the selection process had to be mindful of the potential for information to become outdated and take proactive measures to ensure that the used studies remained relevant and accurate. No participants were recruited for this review; no harm or risk was incurred.

Another limitation was the extraction of articles done by a single reviewer; this leaves relevant information to be missed for this systematic review. The review was conducted with a specific focus on the disease HCV and two specific populations, namely PWIDs and Puerto Ricans. It is worth

noting that there is a significant lack of research on Puerto Ricans and the island's at-risk populations, which makes it difficult to understand their behaviors and patterns related to HCV and stigma. As a result, there is a shortage of information on both populations within Puerto Rico. More research on the Puerto Rican population is necessary to develop strategies and programs targeting certain groups on the island.

### **Recommendations for future research**

Finding relevant information about the link between stigma, Hepatitis C Virus (HCV), and behavior patterns among Puerto Rican people who inject drugs (PWIDs) has been challenging due to limited research on the population. To gain a comprehensive understanding of how stigma affects chronic conditions like HCV, it is essential to broaden the search beyond PWIDs and include chronic conditions at all levels and populations, with a focus on prioritizing evaluations by selecting research studies according to research topic and research question, and by criteria such as similarities of stigma interventions and data collection. Future research should also focus on developing a standardized strategy for tackling stigma by examining various stigmas while keeping the focus on the target population. Concentrating on the perceptions, attitudes, and behaviors of various populations and the negative impact of stigma will help to identify other conditions and understudied populations such as Puerto Rican PWIDs, that may have been overlooked in research.

## **vi. Conclusion**

Due to the lack of healthcare access and insufficient health education on HCV and drug use, stigmatization is likely to persist, which could result in higher infection rates, especially among the PWID population residing in Puerto Rico. Statistics gathered by Watson (2022) reveal that 95% of individuals diagnosed with HCV have reported experiencing stigma at some point in their lives (Watson, 2022) .

HCV stigma can discourage people from seeking treatment and lead to further health issues. Promoting and providing evidence-based information is crucial to reduce stigma. In Puerto Rico, limited access to care and HCV education, migration of medical professionals, and inadequate response from the U.S. government make it challenging to improve public health outcomes. Many people in Puerto Rico struggle to manage their HCV while the public health crisis on the island continues to grow. To address HCV in Puerto Rico, the U.S. government must prioritize providing funding, accurate HCV information, increasing awareness, and access to care and HCV resources. Policymakers, healthcare providers, and

community organizations must work together to improve the healthcare system and better serve those affected.

**Registration and protocol** - No registration number was required for the review.

**Support** - No financial support, such as funders, sponsors, and grants, were used for the review.

**Competing interest** - There was no competing interest in this review.

**Availability of data, code, and other materials**- The materials and supporting information used for this review are available on Google Scholar.

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